

Understanding and addressing stigma through qualitative research

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Understanding and Addressing Stigma through Qualitative Research: Four Reasons Why We Need Qualitative Studies

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Stigmatization is a socially and culturally constructed process, occurring in social interactions, whereby a person is labeled as different and then devalued, resulting in status loss and discrimination. In this article, we present four key arguments as to why qualitative research is imperative to understanding and changing stigma: (a) Stigmatization is complex and qualitative research is well-suited for exploring complex phenomenon; (b) Qualitative research is participatory and offers substantial opportunities for meaningful community engagement, which promotes agency and empowerment, and redresses power imbalances; (c) Qualitative research is imperative to effective stigma reduction; and (d) Qualitative research informs further scientific inquiry and plays an important role in ensuring that we focus on important and relevant aspects of stigma in our research. For each argument, we outline relevant literature and discuss our own experiences with conducting qualitative research on stigmatization. We lean on both theory and practice, paying attention to not only the outcomes of, but also the processes involved, in conducting qualitative research on stigmatization. We then address two criticisms of qualitative research that undermine its legitimacy. We conclude that to better understand stigma, to redress power imbalances, and to inform interventions and further scientific inquiry, we must continue to conduct qualitative research across stigmatized identities and conditions.

Keywords: qualitative research, community engagement, stigma, transgender, HIV/AIDS

Stigmatization is a socially and culturally constructed process by which a person is labeled as different and then devalued, resulting in status loss and discrimination (Link & Phelan, 2014; Pescosolido & Martin, 2015). According to Bos et al. (2013), there are four types of stigma: public stigma, self-stigma, structural stigma, and stigma-by-association (Figure 1). *Public stigma* represents people's cognitive, affective, and behavioral reactions (i.e., discrimination or

enacted stigma) to people with a stigmatized identity or condition, and manifests on an interpersonal level. *Self-stigma* is the anticipation (i.e., anticipated stigma) and internalization (i.e., internalized stigma) of society's negative beliefs about the stigmatized identity or condition, and occurs on an intrapersonal level. *Structural or institutional stigma* is the legitimization and perpetuation of a stigma by society's institutions and ideological systems through, for example, policy and legislation, and occurs on organizational, institutional, or societal levels. Lastly, *stigma-by-association* entails social and psychological reactions to people associated with a stigmatized person (e.g., family and friends) as well as the impact of being connected to a person with a stigmatized identity or condition, and can be considered analogous to Goffman's (1963) courtesy stigma. The four types of stigma are interrelated with public stigma at the core of the other three types. In this sense, the consensual understanding that an identity or condition is devalued (public stigma) leads to anticipated negative reactions and the internalization of society's negative beliefs in people with a stigmatized identity or condition (self-stigma) and/or their associates (stigma-by-association). Public stigma also generates impetus for formalized stigma in structures, institutions, policy, and legislation (structural stigma), and, in turn, these three types of stigma cycle back to reinforce public stigma (Bos et al., 2013; Roozen et al., 2020).

Stigmatization is clearly a process that occurs in social interactions. As such, stigmatization reproduces social inequalities and is perpetuated by the exercise of social, economic, and political power (Hatzenbuehler et al., 2013; Herek, 2014; Link & Phelan, 2014; Phelan et al., 2014; Pryor & Bos, 2015). Accordingly, Phelan et al. (2008) have delineated three functions of stigmatization: to keep people "down" through domination or exploitation, to keep people

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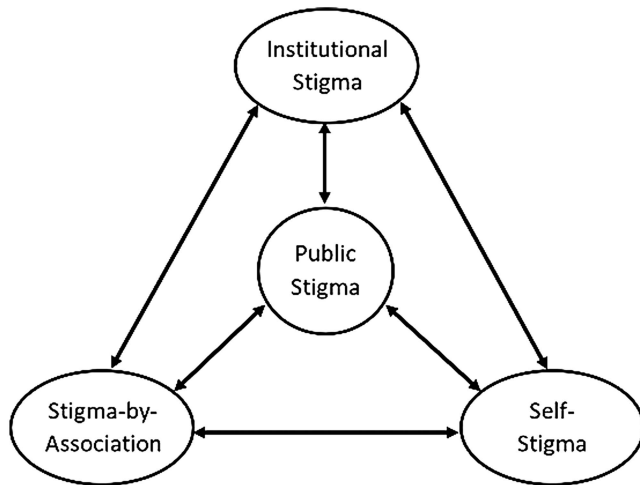
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We wish to firstly acknowledge the people who have shared their experiences of stigma with us. We thank all participants for entrusting us with their experiences to improve understanding of and actions addressing stigmatization. Without participants' willingness and trust, we would not have been able to use our privileged position and strengths in research to better understand and tackle stigma. People's experiences of stigma are first and foremost, and always will be, their own. Additionally, we wish to acknowledge our academic mentors without whom this paper and the experiences described in them would not be possible. For Sarah Stutterheim, this includes Arjan E. R. Bos, John B. Pryor, Gerjo Kok, Rob A. C. Ruiter, Kai J. Jonas, and the late Herman P. Schaalma. For Sarah Ratcliffe, this is Haryana M. Dhillon. We recognize that this work is an extension of our academic lineage and are grateful to be a part of that lineage.

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Figure 1
Four Types of Stigma



Source: Bos et al. (2013)

“in” through norm enforcement, and to keep people “out” as a form of disease avoidance. Stigmatization takes many forms (e.g., avoidance, blame, exclusion) and is prevalent across a number of identities and conditions including, but not limited to, sexual orientation, gender identity, substance use, mental illness, HIV, leprosy, and physical and intellectual disabilities.

This paper discusses why qualitative research is fundamental to understanding and changing stigma. Qualitative research is a broad umbrella term for a collection of approaches to (e.g., ethnography, phenomenology, narrative research, grounded theory, case study research), and methods for (e.g., interviews, focus groups, online data, open-ended survey questions, thematic analysis, discourse analysis), generating knowledge and gaining an in-depth, nuanced, and holistic understanding of people’s experiences, the subjective meanings they assign to their experiences (i.e., sense-making), and the social and cultural contexts and particularities that shape their experiences (Creswell, 2009; Flick, 2009; Hennink et al., 2011; Howitt, 2013). It foregrounds a detailed examination of phenomena from the perspective of those who experience or are impacted by a phenomenon (Creswell, 2009; Flick, 2009; Hennink et al., 2011; Howitt, 2013). Qualitative research is thus well-suited for understanding not only experiences, but also their associated processes and contexts, as well as the social interactions that play a role in people’s experiences (Flick, 2009; Hennink et al., 2011). Much qualitative research is critical and post-positivist, rooted in social constructivism and concerned with promoting social justice and meaningfully engaging with research participants (Howitt, 2013; Levac et al., 2019; Shalowitz et al., 2009). To do qualitative research well, the researcher must be open-minded, curious, empathic, flexible, reflective, and able to listen (Hennink et al., 2011). Qualitative study designs tend to be emergent, data analyses inductive, and findings reflect interpretations of culturally and socially constructed phenomena from multiple perspectives, which acknowledges subjectivity and the existence of multiple “truths” (Creswell, 2009; Howitt, 2013). Influential to subjectivity and “truths” is language, and its important role in the construction of meanings (Willig,

2008). In its essence, qualitative research humanizes science (Hennink et al., 2011).

In this article, we present four key arguments as to why qualitative research is imperative to understanding and changing stigma. For each argument, we outline relevant literature supporting our contentions and discuss our own experiences with conducting qualitative research on stigmatization. We thus lean on both theory and practice, paying attention to not only the outcomes of, but also the processes involved in, conducting qualitative research on stigmatization. We then address two criticisms of qualitative research that undermine its legitimacy.

Stigmatization Is Complex

Our first claim is that we need qualitative research because stigmatization is complex (Mannarini & Rossi, 2018). Qualitative research is designed to capture the rich, contextualized diversity around social phenomena such as stigma by incorporating social context, nuanced multiple “truths”, and “thick” accounts of experiences (Hennink et al., 2011; Polit & Beck, 2010a). It thereby addresses the shortcomings of traditional positivist quantitative approaches and enables us to better understand, and address, complex questions embedded in social structures (Shalowitz et al., 2009). We argue that qualitative research, therefore, has a valuable role in mapping and disentangling the complexities of stigma.

There are few things that make stigmatization so complex. The first is that stigma is embedded in social contexts, which yields a large and diverse web of factors that interact in various ways (Pescosolido & Martin, 2015). Research on stigmatization must acknowledge and consider these interactions, and be sensitive to the social context (Pescosolido & Martin, 2015; Pescosolido et al., 2008). The production of rich data through qualitative research methods enables important contextual factors to be effectively captured within the data and later communicated, thus making the complexity of stigma, and its nuances and variations, clear and apparent (Creswell, 2009; Hennink et al., 2011; Pescosolido & Martin, 2015). In research we previously conducted together with transgender individuals in the Netherlands (Ratcliffe & Stutterheim, in preparation-a, in preparation-b), the data derived from semi-structured interviews on the experiences of being transgender shed light not only on the enacted experiences of stigma within various contexts of life (e.g., at work, with family, in health care and in public spaces), they also showed how those experiences and stigma differed between contexts, and how those stigmatizing experiences were specific to the Dutch context. Similarly, in our previous work on the intersectional stigma of having HIV alongside a history of substance use (Stutterheim, Baas, et al., 2016; Stutterheim et al., 2017), we were able to, with qualitative methods, explore the nuanced ways in which HIV stigma and substance use stigma layer and interact specifically in given contexts such as health care.

Furthermore, characteristics of people (e.g., ethnicity, age, gender, knowledge, beliefs, attitudes, socioeconomic status) or social settings (e.g., cultural norms, service access, laws) impact the experience of stigma and the meanings of those experiences (Hayre & Muller, 2019). Understanding these factors in relation to the experience of stigmatization, in ways that go beyond these characteristics being used as control variables in analyses of

quantitative data, is critical to understanding and disentangling the complexities of stigma, especially if the desire for understanding is driven by a motivation to change stigma. Qualitative approaches are well equipped to unpick and address relationships between knowledge, experience, action, and influencing social factors, and can illuminate embedded meanings (i.e., the “how” and “why” of situations) because they provide evidence directly from the people with lived experiences (Faugier & Sargeant, 1997; Hayre & Muller, 2019). In our studies on the experiences of transgender individuals in the Netherlands (Ratcliffe & Stutterheim, in preparation-a, in preparation-b; Verbeek et al., 2020), we found that our qualitative approach enabled us to identify, from the perspective of individuals with a transgender identity, characteristics of people or social settings that influenced the experience of stigmatization (e.g., religiosity, gender, age, knowledge). Additionally, it became clear that the data acquired through qualitative methods yielded insights that could only be provided directly by people with lived experiences of being transgender. In this context, through the data, we learned about nuances in the way people react to disclosure and we were able to better understand differences in experiences related to passing (i.e., continuum of concealable to non-concealable identity) and gender inequality before, during, and after social and/or medical transition. Similarly, in our studies of stigma-by-association among family members of people with mental illness (van der Sanden, Bos, Stutterheim, Pryor, & Kok, 2015; van der Sanden, Stutterheim, Pryor, Kok, & Bos, 2014), a qualitative approach allowed us to better understand how participants’ gender, their familial relationship to a person with mental illness, and co-residency impacted their experiences of stigma-by-association.

A second reason why stigmatization is complex is because, conceptually, stigma is broad and includes interrelated, heterogeneous parts (Pescosolido & Martin, 2015). It encompasses numerous types of stigma (e.g., internalized, anticipated, enacted) that can be mapped onto various socio-ecological levels (e.g., intra-personal, interpersonal, community, organizational, societal; Bartholomew Eldredge et al., 2016; Bos et al., 2013; Stangl et al., 2013; Hughto et al., 2015), and there are interactions between types and levels. Qualitative research provides the space to explore how stigma types and levels play out in specific social contexts, and allows for the exploration of interactions between stigma types and socioecological levels. Qualitative research is thus not limited to descriptions but can entail explanations and identification of types of stigma function within a given context (Gale et al., 2013). We have seen this in our research on the stigma experiences of transgender individuals in the Netherlands (Ratcliffe & Stutterheim, in preparation-a, in preparation-b), where it became clear how different manifestations of stigma, types of stigma, and socioecological levels interact with each other, yielding insights on the order in which stigma types occur on each socioecological level (i.e., preceding, co-occurring, or proceeding), the extent to which stigma manifestations and types present together, and the ways in which stigma types influence different socioecological levels. By offering the means to systematically and holistically collect, analyze, and present data on the interactions between different phenomena, situations, organizations, and systems, qualitative approaches contribute to better understanding the complexity of stigma that is derived from its various forms or types occurring on various socioecological levels.

A third reason why stigmatization is complex is because stigmatization is an active process (Link & Phelan, 2014; Pescosolido & Martin, 2015) whereby people are kept in, out, or down (Phelan et al., 2008), and this requires engagement by people, organizations, and structures. Qualitative approaches support the collection and reporting of multifaceted, contextualized experiences and information (Creswell, 2009; Flick, 2009; Hennink et al., 2011; Howitt, 2013), and is thus a research method that supports the mapping and detangling of the intertwined process of stigmatization. During the conduct of our qualitative research with transgender individuals in the Netherlands (Ratcliffe & Stutterheim, in preparation-a, in preparation-b), how different types of stigmatization kept individuals in, out, or down across different contexts became apparent, allowing us to link individuals’ positive and negative lived experiences to conceptualizations of stigma and gender. Also, in our research on hepatitis B stigma in Ghana (Adjei, Stutterheim, Naab, & Ruiter, 2019a, 2019b), we established how various beliefs (e.g., that hepatitis B is highly contagious, very severe, and a curse) contributed to certain manifestations of stigma (e.g., avoidance, social isolation, excessive cautiousness in interactions), demonstrating stigmatization as an active process that can be illuminated with qualitative methods.

In summary, qualitative research plays an important role in developing and improving our understanding of the complex social phenomenon of stigma by incorporating social context, nuanced multiple “truths”, and rich accounts of experiences as active processes across types of stigma on various socioecological levels.

Community Engagement and Empowerment

Our second claim is that we need qualitative research because it is participatory and offers substantial opportunities for meaningful community engagement, which promotes agency and empowerment. Placing power with participants is particularly important for those who experience stigmatization. It gives voice to voices that are often unheard or insufficiently heard (Hennink et al., 2011). As such, qualitative research supports activism (Hennink et al., 2011).

Most qualitative research is, in varying degrees, but to a much greater extent than quantitative research, participatory. The values underlying qualitative participatory research approaches are equity, justice, dignity, participation, collaboration, reciprocity, non-othering, accountability, reflexivity, transparency, and flipping power dynamics (Levac et al., 2019; Shalowitz et al., 2009; Sprague et al., 2019). These are all values that are essential to not only understanding, but also changing, stigma.

Because of its participatory nature, where individuals with a stigmatized identity or condition are viewed as experts in their own experience (Anyon et al., 2018; Levac et al., 2019; Sprague et al., 2019), qualitative research offers significant opportunities for meaningful community engagement. Community engagement can be seen as a continuum that moves from outreach efforts to consultation, followed by community involvement, then collaboration, and, finally, shared leadership and decision-making (Sprague et al., 2019). Research projects that engage in the most collaborative end of the continuum—shared leadership—ensure that communities are involved, and adequately compensated for that involvement, in all stages of research including identifying research questions and designing research studies, collecting data, analyzing data or interpreting research results, and disseminating and/or applying the study findings (Gale et al., 2013; Levac et al., 2019; Sprague et al., 2019).

Within the community engagement literature, there are roughly two schools of thought (Brunton et al., 2017). The first is utilitarian and functional. It views community involvement in research as a tool for improving study participant recruitment and/or intervention effectiveness. The second adopts a broader social justice perspective and sees community engagement as a means to support and empower individuals and communities. This approach explicitly seeks to redress power imbalances, create accountability, and reduce inequality. Physical and psychological health improvements, increased study participation, and effective interventions are viewed as positive by-products of this approach. Many models of community engagement merge these two perspectives (Brunton et al., 2017). We align ourselves with the social justice perspective and feel that this is part and parcel to conducting (qualitative) research on stigma, because stigmatization is fundamentally a social justice issue (Corrigan et al., 2005).

An important outcome of reflexive, qualitative research that demonstrates meaningful involvement of communities in collaborative research processes, where decision-making power is shared, is empowerment (Brunton et al., 2017; Shalowitz et al., 2009; Sprague et al., 2019). This kind of research can be transformative for individuals and communities with a stigmatized identity or condition, and can balance the scales of inequity by restructuring power relations between community members and others, including academic researchers (Anyon et al., 2018; Sprague et al., 2019). Participatory qualitative research thus increases agency, improves critical consciousness, and also builds social capital (Anyon et al., 2018; Sprague et al., 2019). These are things that are fundamental to tackling public, self, and structural stigma, as well as stigma-by-association.

Beyond community engagement, the mere sharing of personal experiences can challenge fear and discrimination, and give voice to groups who experience repression and devaluation (Mazanderani & Paparini, 2015). This is very apparent in the history of HIV/AIDS activism, treatment, and care, where talking about experiences has been central to influencing institutional structures, systemic processes and discourse, in addition to being life-saving and influential to the (re)creation of the self and selfhood (Mazanderani & Paparini, 2015). The sharing of experiences through qualitative research thus plays an active role in empowering groups experiencing stigmatization, and in challenging stigma.

In our experience conducting research on stigma, we have indeed found that participatory qualitative approaches that foreground meaningful community engagement are important to the ethical conduct of stigma research, and to the development and advancement of community-approved research agendas, empowerment, and agency. Ideally, all stigma research involves communities, defined here as a social entity with some form of shared (stigmatized) identity or condition (Shalowitz et al., 2009), in all stages of research. We outline below, per research stage, our own experiences with conducting participatory qualitative research in ways that reflect a social justice perspective on community engagement and thus promote agency and empowerment.

Research starts with the identification of a problem or a need, and the subsequent development of research questions that allow us to better understand that problem or need (Bartholomew Eldredge et al., 2016). Once research questions are defined, one or more studies that adequately address the research question are designed. Academic researchers who take a utilitarian approach to community

engagement often do not consult or collaborate with communities when defining research questions or designing studies (Brunton et al., 2017), which can result in the establishment of research priorities that are not shared or condoned by the community in question (Hayre & Muller, 2019). In our stigma research, we follow the lead of the communities that we work with to establish appropriate and relevant research questions. For example, in our research on the experiences of transgender individuals in the Netherlands and in our research on HIV, we work together with a number of community organizations that frequently contact us with questions for which they need or want answers. Once we receive a question, we then, in a formal or informal collaborative team of academic researchers, community members and representatives, and professionals, turn those questions into fitting research questions and appropriate study designs that are sensitive to community nuances. We then seek funding for projects together. Alternatively, we look for ways to conduct the research without funding. Interestingly, AidsFonds, a prominent funder of HIV-related research in the Netherlands, requires academic researchers submitting grant proposals to do so in formal collaboration with the HIV community and in ways that reflect the principles of greater or meaningful involvement of people living with HIV/AIDS (GIPA/MIPA; Joint United Nations Programme on HIV/AIDS, 2007) which includes financial compensation for community involvement rather than reliance on volunteers.

In designing studies, materials must be developed. For qualitative research, this often entails an interview or focus group guide, a checklist of relevant topics, a short demographic survey, and recruitment texts. We seek input before developing materials via, for example, focus groups or informal conversations with community members, and have the collaborative research team review drafts to ensure that the questions and topics are appropriate. This is imperative as the feedback often transforms the language used in study materials. It teaches us, as academic researchers, about the language and terminology that communities prefer when describing their experiences, and this is particularly important in communities that experience marginalization, where words can be empowering or disempowering (person with HIV vs HIV-infected person). One example where we learned about appropriate terminology was in developing materials for a study with individuals of trans experience. In the first draft, we used the term “transwoman” and received feedback that the term “trans women” is more appropriate (see <https://emmanuelle.coach/transgender-using-words-wisely/> for details on why). This kind of learning via community collaboration has been described previously by, e.g., Abelsohn et al. (2015) and Fields et al. (2008).

Once materials are developed, data collection is initiated. In many fields, use of “peers” to collect data is common as this tends to bolster inclusion, in addition to building capacity and skills in interviewers. In our experience doing stigma research, having fellow community members collect data is not without its challenges. While it can indeed build skills and capacity, it is not necessarily fitting for all study participants. We previously conducted research on HIV-related stigma and HIV disclosure among African and Afro-Caribbean people with HIV in the Netherlands (Stutterheim, Bos, Shiripinda, et al., 2012; Stutterheim et al., 2011) and, as part of that study, we trained a number African and Afro-Caribbean community members in interviewing techniques. They subsequently sought out study participants. However, fear of gossip, confidentiality breaches,

and third party disclosure seriously impeded participant inclusion and was not deemed appropriate by people living with HIV (PLHIV) from these communities. In fact, we learned in this process, that many PLHIV in African and Afro-Caribbean communities in the Netherlands preferred to be interviewed by an “outsider” than by an “insider”. We do have positive experiences using snowball sampling techniques (Frost, 2011) in qualitative research projects but this reflects a more utilitarian approach to community involvement in data collection.

The next phase of research in which communities can be engaged is data analysis and interpretation. We do not have experience engaging communities in actual data coding and analyses, although we do recognize the capacity-building value of including communities in coding and analyses. We do have significant experience involving participants and communities in the interpretation of data. This has occasionally taken the form of member checks whereby summaries of participant transcripts are returned to participants for review (Ratcliffe & Stutterheim, in preparation-a, in preparation-b). More frequently, and more in line with a social justice perspective on community engagement, communities have been involved in data interpretation by conferring with collaborative research teams, through roundtable meetings with community representatives, and via presentations of preliminary findings to community members. For example, in the previously mentioned work on HIV stigma in African and Afro-Caribbean communities in the Netherlands (Stutterheim, Bos, Shiripinda, et al., 2012; Stutterheim, Bos, van Kesteren, et al., 2012; Stutterheim et al., 2011), we presented preliminary findings to community leaders and asked them to reflect on those findings. Similarly, we have returned preliminary findings on stigma experiences to the transgender communities we work with to be reviewed for appropriate language and to ensure that data interpretation was reflective of the transgender community’s experiences (Ratcliffe & Stutterheim, in preparation-a, in preparation-b).

The final research phase is the dissemination and implementation or application of research findings. Here, we find it important to disseminate findings in formats that are fitting for the communities that are the focus of research. This means going beyond drafting and distributing technical reports and peer-reviewed journal articles; it requires us to present findings in non-academic formats that can be easily understood and effectively used by community organizations to lobby for social change (e.g., fact sheets, project websites). Collaboration with community members in the drafting of these dissemination products is paramount. Our experience with dissemination and, to an even greater extent, the subsequent implementation or application of research findings in practice is that ownership of the dissemination products (e.g., factsheets, project websites, and stigma reduction interventions) should be in the hands of community organizations. In our work with both the transgender community and the HIV community in the Netherlands, we have witnessed how qualitative research findings presented in accessible formats have been used to develop new policy, to guide funding priorities, and to support national advocacy and lobby agendas led by community organizations.

In short, we contend that qualitative research on stigmatization is necessary because it is participatory and offers substantial opportunities for meaningful community engagement. Collaborating meaningfully with communities that experience stigmatization across all stages of research promotes agency and empowerment, and redresses power imbalances, and this is imperative in our efforts to tackle stigmatization.

Stigma Reduction

Our third claim is that qualitative research is necessary for stigma reduction. Effective stigma reduction requires systematically developed interventions that are based on theory and evidence (Bartholomew Eldredge et al., 2016; Bos et al., 2008). The *Intervention Mapping* protocol offers a sound framework for the development, implementation, and evaluation of multifaceted stigma reduction interventions that target the various types of stigma (public stigma, self-stigma, structural stigma, stigma-by-association) through a variety of actors across socioecological levels (individual, interpersonal, community, organizational, societal). The Intervention Mapping protocol comprises six steps: (a) conducting a needs assessment and drafting a logic model of the problem; (b) specifying program outcomes and objectives; (c) designing the intervention by selecting theory and evidence-based methods for behavior change (in this case stigma) and their practical applications; (d) producing and pre-testing the program; (e) planning for program implementation; and (f) planning for program evaluation (Bartholomew Eldredge et al., 2016; Roozen et al., 2020; Ruiter et al., 2013). In Intervention Mapping, there are also six *Core Processes* that underlie each planning step. These are: (a) pose questions; (b) brainstorm possible answers; (c) review empirical findings from published research; (d) find theoretical support; (e) identify and address the need for new research; and (f) complete and assess the list of possible answers (Bartholomew Eldredge et al., 2016; Ruiter & Crutzen, 2020). Qualitative research is a key component of a number of steps in the Intervention Mapping protocol and is reflected in the fifth step of the Core Processes (Bartholomew Eldredge et al., 2016; Ruiter & Crutzen, 2020).

For example, Intervention Mapping starts with a needs assessment to ascertain the determinants, and possibly also the outcomes, of a problem (i.e., stigmatization) as well as the context for the intervention including the population, setting(s), communities, and environmental context in which stigma reduction is called for (Bartholomew Eldredge et al., 2016; Peters, 2014). Qualitative research is important in needs assessments for stigma reduction interventions because it provides a nuanced understanding of stigma in a given context from the perspective of those to be targeted by stigma reduction efforts, and because it allows for the identification of relevant determinants and outcomes of stigmatization that can subsequently be tested for their magnitude in, for example, a quantitative survey study, and targeted for intervention (Bartholomew Eldredge et al., 2016; Hayre & Muller, 2019; Peters, 2014). In short, qualitative research in needs assessments enables us to better understand the dynamics of stigma including its behavioral and environmental causes before intervening. It also helps us to establish relevant points, contexts, or settings for intervention (Bartholomew Eldredge et al., 2016). Some of our research has inadvertently functioned as needs assessments for intervention projects that were later established as a result of the study findings (e.g., Stutterheim, Bos, Shiripinda, et al., 2012; Stutterheim, Bos, van Kesteren, et al., 2012; Stutterheim et al., 2011). Other studies were explicitly conducted as a needs assessment for a planned stigma reduction intervention. For example, in preparation for a stigma reduction intervention that focused on reducing HIV-related stigma in the Dutch health care sector, we conducted qualitative research on stigma and disclosure of HIV status in the Dutch health care sector from the perspectives of both PLHIV and health care providers (Stutterheim, Roberts, et al.,

2017; Stutterheim, Sicking, et al., 2016; Stutterheim et al., 2014), and we explored the workplace experiences of health care providers living with HIV (Stutterheim, Brands, et al., 2017) such that relevant determinants of stigma and points of intervention could be identified.

Qualitative research is also important in the actual development of stigma reduction interventions. Once program goals and objectives are defined, theory and evidence-based methods for stigma reduction can be selected. We have a broad evidence base supporting a number of stigma reduction strategies including, but not limited to, interpersonal contact (Allport, 1954; Bartos et al. 2014; Corrigan et al. 2012; Dalky, 2011; Dickstein et al., 2010; Doley et al., 2017; Livingston et al. 2012; Maunder & White, 2019; Morgan et al., 2018; Stubbs, 2014; Yamaguchi et al., 2013), empathy induction (Batson et al., 2002), and perspective taking (Todd et al., 2012) for targeting those who stigmatize; and planning coping responses (Dobson et al., 2019; Mittal et al., 2012; Hughto et al., 2015), improving psychological flexibility via Acceptance and Commitment Therapy (Livingston et al., 2012; Masuda et al., 2012), counselling or support provision (Sommerland et al., 2017), and skills and resilience building (Mittal et al., 2012; Pantelic et al., 2019) for those who experience stigmatization. Once these and/or other theory- and evidence-based methods for stigma reduction are selected, program planners develop practical applications of stigma reduction methods into a coherent program with defined themes, sequence, and scope (Bartholomew Eldredge et al., 2016). The practical applications must be appropriate for those for whom the intervention is developed and must take into account the parameters for their use and effectiveness (Kok, 2014). Here, qualitative research plays an important role again, particularly with respect to ascertaining the conditions under which selected methods can be applied in a given context or via a given communication channel or vehicle. We have experience doing this in the context of the HIV-related stigma reduction intervention we developed for the Dutch health care sector. When we initially proposed the intervention to the funder, our intention was to develop a modulated training program for health care providers. Qualitative research made it abundantly clear that health care providers in the Netherlands have limited contact and experience with HIV, and thus would not prioritize an extensive training program. We therefore decided to develop a short, easily accessible online intervention instead (www.positiefzorgt.nl), as this was more likely to be acceptable to health care providers. Without qualitative research, we would not have established this.

Qualitative methods are also well-suited for the pretesting of intervention messages and materials to ensure that components of intervention products (e.g., websites, apps, brochures, training materials, films and documentaries) reflect relevant characteristics of the intended participants' needs, cultural preferences, knowledge, attitudes, and beliefs (Bartholomew Eldredge et al., 2016; Hayre & Muller, 2019). It is advisable to do this before producing materials and then again after production with prototypes of program materials in order to determine if further tailoring or targeting is necessary, if the language used is appropriate, and if there is sensitive or controversial content that needs to be reworked (Bartholomew Eldredge et al., 2016; Fields et al., 2008). In our HIV stigma reduction intervention project, we did this via our collaborative team that included PLHIV and representatives of PLHIV, and also directly with members of the HIV community where we engaged in multiple rounds of feedback in the development and production process. One component of the online intervention was digital

storytelling through short films (reflecting vicarious contact for those who stigmatize and modeling for PLHIV as the methods). For each film, we asked members of the HIV community and health care providers to review and provide feedback on preliminary versions of the short films.

Once program materials are produced, implementation follows. Evidently, engaging with potential adopters, implementers, and maintainers, and planning for implementation, should occur right from the outset of any stigma reduction project and should reflect participatory processes (Bartholomew Eldredge et al., 2016; Fernandez et al., 2019). In step 5 of Intervention Mapping, also termed *Implementation Mapping* (Fernandez et al., 2019), program planners apply again the previous steps of Intervention Mapping but then in the context of program adoption and program use. The tasks involved are: (a) conducting an implementation needs assessment and identifying program adopters and implementers; (b) stating adoption and implementation outcomes and objectives; (c) choosing theoretical methods to design implementation strategies; (d) producing implementation protocols or materials; and (e) evaluating implementation outcomes. Here, too, qualitative methods are important as they enable us to not only identify adopters, implementers, and maintainers, but also to ascertain or verify determinants of the stigma intervention's adoption, implementation, and maintenance, while accounting for important contextual factors that influence the relationships between implementation strategies, their impact on determinants, and the subsequent influence on implementation outcomes (Fernandez et al., 2019). In our HIV-related stigma reduction intervention for the Dutch health care sector, we did not pay as much attention to implementation as we should have. We did identify adopters, implementers, and maintainers through qualitative research, but we did not focus sufficiently on factors that could promote or impede the successful implementation of this intervention. This was an important lesson learned.

The final step in Intervention Mapping is planning for evaluation (Bartholomew Eldredge et al., 2016). Comprehensive evaluations of behavior change interventions, including stigma reduction interventions, comprise both effect and process evaluations. Effect evaluations are quantitative assessments of intervention outcomes while process evaluations are qualitative studies on the way in which interventions were implemented. Process evaluations employing qualitative designs are fundamental in determining whether an intervention was implemented as intended (fidelity) and whether aspects of the broader social environment affected implementation (context). Additionally, process evaluations provide insight on barriers and facilitators to implementation, and the extent to which intended participants were satisfied with the intervention. Further, process evaluations allow for critical reflection on intervention design and provide context for understanding whether an intervention's success or failure can be attributed to the actual intervention or to the way in which it was implemented or applied (Bartholomew Eldredge et al., 2016). See Flórez et al. (2017) and Payán et al. (2019) for examples of process evaluations of stigma reduction interventions.

In the context of our online HIV stigma reduction intervention for the Dutch health care sector, we indeed employed qualitative methods for the process evaluation. Specifically, we used a "think aloud" approach (Lyons et al., 2015) in interviews whereby participants (8 PLHIV and 8 health care providers) freely navigated the online intervention while the interviewer posed open-ended

questions that encouraged participants to appraise the various website components (short films, quizzes, and information provision) as well as the graphic design and structure of the online intervention. Participants were also asked to convey what they perceived to be strengths and weaknesses of the intervention, their previous familiarity with the intervention, and the extent to which they perceived it to meet their expectations or needs (Stutterheim & Bos, unpublished data). The findings showed that, although the intervention was deemed relevant, appropriate, and clear, meeting the needs of its target population, it was not known by most participants, reflecting the need to pay additional attention to further implementation, particularly among health care providers. This could not have been ascertained with only a quantitative effect evaluation.

In summary, qualitative research is imperative in the development, implementation, and evaluation of stigma reduction interventions. However, not all qualitative research on stigmatization occurs in the context of an intervention. There are many examples of qualitative studies conducted for the purposes of simply understanding a given population or community's experience with stigma (for syntheses of qualitative studies on stigma, see e.g., Chambers et al., 2015; Coleman et al., 2017; Jeong et al., 2016; Malterud & Ulriksen, 2011; Wood et al., 2015), and while many qualitative studies do not formally intend to reduce stigma, inadvertently they do. In fact, Mazanderani and Paparini (2015) argue that qualitative research focusing on lived experiences plays a vital role in normalizing stigmatized identities and conditions. The stories participants tell in interviews or focus groups, and thus also the stories that academic researchers retell in presentations and publications, redefine what it means for a given set of people to live with a given stigmatized identity or condition (Mazanderani & Paparini, 2015). As such, qualitative research forms part of a wide discursive normalization of the stigmatized identity or condition. Also, the mere participation in qualitative studies, particularly when participative and reflective of meaningful community engagement, can directly impact stigma by reducing internalized or self-stigma (Fields et al., 2008; Sprague et al., 2019). This is because being part of qualitative research on stigma often encourages reflection on, and the reattribution of, society's negative beliefs about the stigmatized identity or condition.

Furthering Scientific Inquiry

Our fourth claim is that qualitative research is important for furthering scientific inquiry (Creswell, 2009). It ensures that future research questions and study designs are informed by the lived experiences of individuals and/or communities with a stigmatized identity or condition, and reduces the risk that research findings are driven by (potentially flawed) assumptions on the part of non-community member researchers (Hayre & Muller, 2019). This is imperative when conducting research on complex social phenomenon that have multiple nuances and contextualized "truths" (Doucerein et al., 2016), as is the case with stigmatization. Additionally, qualitative research has substantial capacity to complement and enhance quantitative research approaches and can strengthen the reliability and validity of quantitative research findings. This is particularly the case when mixed methods are used (Bartholomew Eldredge et al., 2016; Creswell & Plano Clark, 2010; Plano Clark & Creswell, 2008; Teddlie & Tashakkori, 2009).

Mixed methods research combines the complementary strengths of qualitative and quantitative approaches within a study or project investigating the same phenomenon (Creswell & Plano Clark, 2010; Greene, Caracelli, & Graham, 1989; Leech & Onwuegbuzie, 2009). This combination improves our understanding of stigma, adds credibility to research findings, enables us to better evaluate and explore patterns and new insights, and can contribute to the development of sound stigma measures (Bartholomew Eldredge et al., 2016; Creswell & Plano Clark, 2010; Plano Clark & Creswell, 2008; Teddlie & Tashakkori, 2009). The strategic and judicious blending of qualitative and quantitative data also holds promise for enhanced generalizability of overall research results, with rich qualitative data leading to well-grounded meta inferences that complement and contextualize quantitative findings (Polit & Beck, 2010a). In qualitative research, there is an ongoing interplay between data collection, analysis, and theory development, and this offsets and brings balance to the strict sequential and mutually exclusive stages of quantitative data collection and analysis. Resultingly, qualitative approaches can highlight subtle inconsistencies worth further exploration and provide participant-driven new and worthwhile insights and lines of inquiry, which would not have become apparent through quantitative approaches or data (Gale et al., 2013). Evidently, the multiple perspectives offered by combining qualitative studies with quantitative studies yield a more complete understanding of the research problem than if we were only to conduct quantitative studies (Bartholomew Eldredge et al., 2016; Creswell, 2009; Shorten & Smith, 2017; Steckler et al., 1992). In the current stigma literature, we have seen, alongside an increased interrogation of how we conceptualize and measure stigma, also a rise in mixed methods studies of stigma (Pescosolido & Martin, 2015), and this is, in our view, a promising development in stigma research.

Creswell and colleagues describe four models for mixed methods research: (a) explanatory sequential; (b) exploratory sequential; (c) convergent parallel; and (d) embedded (Creswell, 2009; Creswell & Plano Clark, 2010; Creswell & Zhang, 2009). Explanatory sequential mixed methods research utilizes qualitative research to explore and explain results of quantitative research (Creswell & Zhang, 2009). It supports the "digging out" of nuances and contextual experiences within statistical findings. In reverse, explanatory sequential mixed methods research utilizes quantitative approaches to expand and quantify qualitative findings. Here, qualitative research provides detailed contextualized and community-driven directions for future research questions, which are subsequently explored quantitatively. This advantageously enables the elicitation of statistical data, while maintaining the ecological validity derived from context relevant qualitative research. It also offers a sound framework for developing or adapting stigma measures, whereby codes and quotes from qualitative data become variables and survey items that are subsequently pre-tested and qualitatively assessed for (cultural) appropriateness and content validity, and then validated further with quantitative measures (Creswell & Plano Clark, 2010; Onwuegbuzie et al., 2009; Zhou, 2019). For an example, see Shellenberg et al. (2014).

The third model of mixed methods research, namely the convergent design, involves the simultaneous, equal, and parallel use of qualitative and quantitative approaches (Creswell & Zhang, 2009; Steckler et al., 1992). Its aim is to better understand a construct or event from the perspectives of two different types of evidence (Creswell & Zhang, 2009). It requires that qualitative and

quantitative methods intentionally be used simultaneously to assess the same conceptual phenomenon (Greene et al., 1989). This entanglement, rather than separation, helps to ensure that results provide holistic perspectives. It offsets biases and enhances the validity or credibility of both the quantitative and the qualitative research findings (Creswell & Zhang, 2009). The fourth model is the embedded mixed methods model which sequentially or concurrently nests qualitative components in a larger quantitative study or that nests quantitative data collection into a larger qualitative study (Creswell & Zhang, 2009).

In our own stigma research, we have experience with the use of qualitative methods in all four mixed methods research models, and have moved back and forth between the models within and across research projects. For example, in a broader study of HIV-related stigma in the Netherlands, we first used an explanatory sequential approach. Specifically, we conducted a cross-sectional survey on HIV-related stigma experiences across settings and their impact on psychological well-being, and ascertained that stigma experienced in health care settings and from family significantly predicted psychological distress (Stutterheim et al., 2009). We then followed up that survey with semi-structured interviews which we conducted with a subset of disproportionately affected PLHIV (i.e., PLHIV with an African and Afro-Caribbean migration background) where we focused on their stigma experiences in these and other settings (Stutterheim, Bos, Shiripinda, et al., 2012). Our intention was to tease out the various manifestations of stigma across contexts, as well as their impacts, within the overarching narrative of PLHIV's stigma experiences (Hayre & Muller, 2019), and the particularities of the experiences of African and Afro-Caribbean PLHIV. The interviews thus helped provide context for why stigmatization from health care providers and family members was so detrimental. Subsequently, we honed in on the health care sector with a cross-sectional survey study that measured the prevalence of particular manifestations of HIV-related stigma in health care settings (e.g., double gloving, unnecessary referrals, confidentiality breeches) and with whom these manifestations occur (e.g., nurses, physicians, specialists, support staff), which is reflective of an exploratory sequential approach where quantitative research is employed to quantify qualitative findings. In this process, we developed the measure of relevant manifestations of stigma in health care settings described above using findings from a focus group discussion with PLHIV and professionals working in HIV. We then returned again to qualitative research where we built further upon the quantitative findings on HIV stigma in health care settings, and contextually explored both PLHIV's and health care providers' perspectives on their interactions through semi-structured qualitative interviews (Stutterheim et al., 2014). This can be seen as a return to an explanatory sequential model.

We also have experience with a convergent parallel mixed methods approach, where qualitative and quantitative data are used in parallel to better understand a phenomenon. We are currently doing this in the context of a needs assessment for a self-stigma reduction intervention for PLHIV in the Netherlands (van der Kooij et al., submitted; van der Kooij et al., in preparation). Strictly speaking, data collection in these studies was not entirely parallel but data analyses were. The quantitative cross-sectional survey study and the qualitative interview studies were conducted and analyzed separately to provide a more comprehensive triangulated understanding of self-stigma in MSM PLHIV and PLHIV with a migration background. Lastly, our experience with embedded mixed

methods research includes the embedding of qualitative components in the form of open-ended questions in quantitative surveys. We have done this in surveys with PLHIV and with older LGBTIQ+ individuals but this data has not yet been analyzed or reported.

In sum, the inclusion of qualitative studies in the context of various forms of mixed methods research is highly valuable in stigma research because these qualitative studies contextualize quantitative research results and strengthen their reliability and validity, because qualitative studies in mixed methods projects ensure that appropriate community-driven research questions and measures of stigma are developed and answered, and that the quantitative study materials are in line with community needs, and because, together, qualitative and quantitative studies generate a more complete understanding of stigma.

Legitimacy of Qualitative Research

Stigma as a phenomenon of study traditionally bridges the disciplines of sociology and psychology. Within sociology, the position of qualitative studies is relatively well established. Unfortunately, in psychology, this is less so the case (Sullivan & Forrester, 2019). Although there is a long tradition of qualitative research in psychology, it is a marginalized history that has been overshadowed by more positivist approaches that use quantitative evaluative criteria (Burman & Whelan, 2011). As such, qualitative research has been criticized for being "soft" and overly subjective—anecdotal even, for being subject to extensive researcher bias, and for lacking generalizability (Burman & Whelan, 2011; Chowdhury, 2015; Cope, 2014). This has significant implications for both the acquisition of funding for qualitative projects and the publication of qualitative findings (Denzin, 2018). In light of this, we would like to address two main criticisms of qualitative research: (a) its subjectivity and (b) its apparent lack of generalizability.

The notion of objectivity, and its corollary, subjectivity, in research is a problematic one. It presupposes singular truths and our capacity as human beings to ascertain them (Burman & Whelan, 2011; Willig, 2008). In a positivist context, qualitative research is construed as highly subjective and thus inferior (Burman & Whelan, 2011). Research questions are considered to be driven by the (personal) interests of the researcher, data are collected from small and non-probable samples, and findings are actively constructed by researchers who may overidentify with research participants and/or overinterpret data (Burman & Whelan, 2011; Carminati, 2018; Chowdhury, 2015). Then, research findings are "cherry-picked" such that the best possible "story" that meets the demands of journals' scope and word count limits is presented (Burman & Whelan, 2011). What is important to keep in mind is that subjective decisions made in the research process occur not only in qualitative studies but also in quantitative studies, and in both contexts, we have "checks and balances" to ensure that we use sound methodology and that we act ethically (Burman & Whelan, 2011). What is most important in this regard is transparency about the choices we make and why we make them (Flick, 2009; Holloway & Wheeler, 2010). Additionally, reflexivity is key. We must consider and convey the ways in which our person, our background, our social position, power and privilege, and our structural and ideological influences impact upon the research we do (Burman & Whelan, 2011; Willig, 2008). Also, there are numerous ways in which we can ensure quality in qualitative studies. Examples include member checking,

triangulation, searching for deviant cases, peer debriefing, and thick description (Flick, 2009; Holloway & Wheeler, 2010).

The second major criticism is the apparent lack of generalizability of qualitative findings. Generalizability is a process whereby we draw broad conclusions from specific instances; we infer what we do not see based on what we have seen (Polit & Beck, 2010b). Because qualitative research explores particularities in small samples, the claim is that the findings cannot be considered to hold for anyone other than the research participants (Polit & Beck, 2010b). However, the criticism refers to only one particular form of generalizability, namely, statistical generalizability (Carminati, 2018; Polit & Beck, 2010b; Smith, 2018) whereby a sample must be representative for the population under study (Polit & Beck, 2010b) and this is not the case when sampling is purposive. Consequently, many articles reporting qualitative findings include a lack of generalizability as a limitation (Smith, 2018). This is not advisable for two reasons: First, endeavoring to achieve statistical generalizability does not fit with the ontological and epistemological foundations of most qualitative research where multiple realities are acknowledged and knowledge is considered to be constructed (Carminati, 2018; Smith, 2018). Second, we contend that qualitative research, particularly qualitative research on stigma, can and should be generalized (Polit & Beck, 2010b; Smith, 2018). Without generalization, the utility of research findings for bringing about social change through interventions or policy is limited (Carminati, 2018; Polit & Beck, 2010b; Smith, 2018). We do stigma research because we want to change something, because we seek social justice for marginalized individuals, because we want to redress power imbalances. If we cannot take our findings and put them to work for the betterment of stigmatized individuals and communities, then our research has little practical relevance. We should thus endeavor to generalize our results to other individuals, populations, contexts, locales, and times via what is termed theoretical, conceptual, or analytic generalizability (Carminati, 2018; Polit & Beck, 2010b; Smith, 2018). This kind of generalizability occurs when research findings reinforce concepts or theories (Polit & Beck, 2010b; Smith, 2018). We do this by exploring stigma across contexts and settings, and in various populations, by being reflexive, and by triangulating across sources, researchers, and analytical approaches. We can also promote analytic generalizability by digging deep and inductively into our data and conveying the findings with thick descriptions (Burman & Whelan, 2011; Flick, 2009; Polit & Beck, 2010b; Smith, 2018).

In short, if we acknowledge that subjectivity exists across all research and that qualitative findings have analytic generalizability, we are in a better position to improve the legitimacy of qualitative research methods. Legitimacy is also gained when academic organizations (e.g., APA, BPS), funders, and publishers recognize the value of qualitative research and apply quality criteria that align with the method. This special issue on qualitative research on stigma is a prime example of how publishers can consciously advance a research agenda that creates space for both quantitative and qualitative research.

Conclusion

The purpose of this paper was to outline four arguments supporting the inclusion of qualitative studies in stigma research, namely: (a) stigmatization is complex and qualitative research is well-suited for exploring complex phenomenon; (b) qualitative research is

participatory and offers opportunities for meaningful community engagement, which promotes agency and empowerment, redresses power imbalances, and supports activism; (c) qualitative research is imperative to effective stigma reduction; and (d) qualitative research informs further scientific inquiry and plays an important role in ensuring that we focus on aspects of stigma that are most relevant to those impacted and affected by stigmatization. We hope that this paper will serve as impetus, among stigma researchers and those who seek to reduce stigma, to include qualitative research in their efforts to better understand stigma, redress power imbalances, develop interventions, and further scientific inquiry into stigma, its causes, and its consequences.

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